

New Commission Member

Governor Mike Huckabee appointed Joe McNiel to the Arkansas Spinal Cord Commission (ASCC) on September 29, 2000. Joe has lived with a spinal cord injury since June of 1986 when a mobile home he was working on fell on him. He and his wife Linda and their children live in the Spring Hill community outside Hope, Arkansas where Joe raises cattle and works as a personal trainer.

A well known wheelchair athlete over the past decade, before his recent retirement, Joe was a regular participant in wheelchair road races and marathons around the state and the nation. Joe brings a unique experience to the Commission and has already become an active member. He replaces Deanna VanHook, who recently moved out of state, to fulfill a term through January 2009.



Welcome! Joe McNiel, ASCC's new commission member from Hope, AR.

Disability Rights Center Advocates for You

The Disability Rights Center (DRC) is a federally mandated protection and advocacy system that serves people with disabilities in the state of Arkansas. Its mission is to protect the human, civil and legal rights of individuals with disabilities. It is a DRC policy to assure confidentiality of client information and to respond to client complaints. Some of the programs provided include CAP, PAIR and PAAT.

What is CAP?

Client Assistance Programs provide assistance in informing and advising all clients and client applicants of all available benefits under the Rehabilitation Act, and, upon request of such clients or client applicants, to assist and advocate for such clients or applicants in their relationships with projects, programs and services provided

under the Act, including assistance and advocacy in pursuing legal, administrative or other appropriate remedies to ensure the protection of the rights of such individuals and to facilitate access to the services funded under the Act through individual and systemic advocacy. The client assistance program provides information on the available services and benefits under the Act and Title I of the Americans with Disabilities Act of 1990 to individuals with disabilities in the State, especially with regard to individuals with disabilities who have traditionally been unserved or underserved by vocational rehabilitation programs.

Federal Mandate - (CAP) Rehabilitation Act - (P.L. 105-220), 29 U.S.C. 732. Funded through U.S. Dept. Of Ed., Rehabilitation Services Administration.

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SPINAL COURIER

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Cheryl L. Vines
Executive Director

Thomas L. Farley
Dee Ledbetter
Co-Editors

Commission Members:
Sandra Turner, Chair
Sheila Galbraith Bronfman
James Miller
Joe McNiel
Russell Patton

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Visit our website at:
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or e-mail us at:
arksc@aol.com

With Thanks

Donations this quarter from:

Tommy Miller
Joyce Raynor
Jean Tate

In Memory of Martha Henderson
Maude Simmons

In Memory of Ella Garner
Lois Pfeiffer

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Web Sites

Dear Editor:

I'm wondering if any of the *Spinal Courier* readers have found particularly informative or helpful web sites. Topics I would like to learn more about include: quality of life issues, accessibility, durable medical equipment, etc.

Many of my clients now have computers with internet access and are

increasing their potential knowledge base, which could be useful information for one and all.

Robert Griffin
ASCC Case Manager
Russellville, AR

Editor's Note: Readers please see the related article, "Life on the Internet," found in this issue on pages 6 and 7.

From the Director

As you read this we have begun a new year (maybe a new millennium, depending how you count years). However you count the years, I hope 2001 brings you great joy!

These days it is sometimes difficult to stop and enjoy our activities and accomplishments. We seem to move from one thing to another, never stopping to bask in the glow of what we have done or to give due to those who have helped us do it! So this year I want to start off right by saying **thank you** to those of you who have been of such great help to the Commission and to me.

So often, over the past several years, we have asked many of you for your help in completing our research projects. These projects are important to the Commission and our mission, as they provide us with information and knowledge about life with spinal cord disability in Arkansas. We use the information in our attempts to obtain and maintain our funding, as well as in developing our programs. We could not do it without you!

Thank you to each of you who have filled out a survey, answered a phone interview, attended a focus group or a clinic when we asked you. We appreciate your help and your commitment to making life better for others with spinal cord disabilities.

Thanks, too, to all the health care professionals, family members and friends who have taken time to share your expertise with us. Your help and experience are invaluable to our mission.

And finally, I want to say **thank you** to the staff of the Spinal Cord Commission, who for 25 years have been committed to making sure that folks with spinal cord disabilities in our state get the services they need. I'm proud to work with such a dedicated group of people!

A new year must be good, when you start it off by being **thankful!**

Cheryl Vines

Kruegger's On Board

By Sharon McCoy, ASCC Case Manager, West Memphis, AR

ASCC client Jimmie Richardson of West Memphis, AR would like everyone to welcome Kruegger, the newest member of his family. Kruegger is a two-year-old Labrador Retriever mix service dog acquired from Canine Companions for Independence (CCI). CCI is a nonprofit organization that better the lives of people with disabilities by providing highly trained assistance dogs and ongoing support to ensure quality partnerships.

According to Jimmie, Kruegger is the best service dog in the world. Kruegger has a large range of skills that help in Jimmie's daily activities. Not only does Kruegger retrieve items for Jimmie, he has been trained to handle financial exchanges from high counter tops to Jimmie's chair height. Both

Jimmie and Kruegger had to undergo intense and rigid standards to make sure that they were compatible to each other's personalities. There was also intense course work and then a certification test to use the canine companion in public.

So far, Jimmie has taken Kruegger from stores such as WalMart to his college classrooms. "On each outing Kruegger has performed admirably," remarked Jimmie.

Unfortunately, the waiting list is extremely long for a canine companion and restrictions do apply. Jimmie had nearly a three-year wait for a spot in the program. "Still," said Jimmie, "in the end it has all been worth it." Join us in wishing Jimmie and Kruegger well in their many adventures!



Jimmie Richardson and Kruegger are ready for life's adventures together!

For more information, please contact the CCI National Headquarters, 2965 Dutton Avenue, PO Box 446, Santa Rosa, CA 95402-0446, **707-577-1770** (voice), **707-577-1756** (TTD), **707-577-1711** (FAX) or **info@caninecompanions.org** (e-mail).

Tips for Healthy Living: Pain

Pain is a major issue for many individuals with SCI. Those with pain can fall into a repeating cycle of pushing themselves until the pain becomes severe enough that they must rest. This cycle often results in negative consequences like periods of increased pain and fatigue, anticipating pain, increased tension, worry/anxiety, a decrease in the ability to do daily activities and a tendency to totally avoid daily activities.

Pacing of activities is a method that may help to manage everyday pain and improve quality of life.

1. List all activities that you frequently overdo that result in an increase in your pain or fatigue. For example, if typing on a computer tends to increase your pain, list "typing on a computer."
2. When doing each activity on

your list, make a note of the time that it takes for you to experience an increase in pain or fatigue. For example, make a note if your pain or fatigue increases after 30 minutes of typing on the computer.

3. Set a time limit for doing the activity that is well below the point when you experience an increase in pain or fatigue. When you reach that time, **stop and rest**. For example, stop and rest after 15 minutes of typing on the computer.
4. Return to the activity after your rest period. The time that you spend resting will vary. You want to have enough rest time for you to continue the activity as outlined in numbers 2 and 3.
5. Do not get in a rush to complete any activity. You should **slowly** increase your endurance by

increasing the amount of time that you spend doing the activity and **always** include adequate rest periods.

This activity/rest cycle is not a cure for pain. It is a simple method that has been shown to improve the quality of life for many individuals with SCI. Pacing of activity should work for you if you stick to it. But it is important to always talk to your doctor before you try any new treatment.

Information on *Pain* was provided by John D. Putzke, PhD, a research postdoctoral fellow with the UAB Department of Physical Medicine and Rehabilitation.

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Do Yourself a Favor – Exercise!

By Tom Kiser, M.D., ASCC Medical Director

The benefits of exercise are widely known—it decreases the risk of heart disease, obesity and hypertension, plus makes us feel better. If it could be prescribed in pill form, I would have almost all my patients on exercise (and I would be taking it myself!). It is especially important to think about exercise as we celebrate the holidays, so we can avoid the problems associated with being around too much good food—weight gain.

To keep from gaining weight we have two choices: **eat less** and/or burn more calories by **exercising**. The body is an efficient machine and when we eat less it decreases the rate at which calories are burned. So to increase the rate at which the body burns calories, we need to exercise. This is not an easy task when you have a spinal cord injury with either paraplegia or tetraplegia.

You can exercise by just increasing your routine daily physical activity. Use your manual wheelchair to exercise, choose to dress yourself

This has the double benefit of increasing your independence and decreasing the work load on your care giver.

even if it takes more time or choose to transfer yourself even though it is faster if someone else does it for you. This has the double benefit of increasing your independence and decreasing the work load on your care giver. It also improves your strength and endurance, and helps you burn more calories and, if combined with decreased food intake, possibly helps you to lose

weight. If your choice is a more aggressive form of exercise, you must consider any cardiac risk factors you may have that increase your risk of a heart attack. You are at increased cardiac risk if:

- Your mother or father had a heart attack at a young age (younger than 55 for a male, or younger than 65 for a female)
- You are a male over 45 or a female over 55
- You smoke
- You have diabetes
- You have high blood pressure (140/90)
- Your cholesterol is more than 200 mg/dl
- You have hypertension
- You are obese
- You lead a sedentary life style

If you have **more than two** of these risk factors you may want to discuss your proposed exercise program with your physician and undergo an exercise test with an arm exercise machine while having your heart monitored with an EKG.

Here are some exercise ideas to consider as you ponder whether you can start an exercise program for yourself:

1. Arm exercise with a table top arm powered bicycle machine with friction resistance.
2. Use your manual wheelchair to exercise by pushing it for 10 to 20 minutes to increase heart rate.
3. If you have paraplegia, talk to your physician about getting



braces to walk with a walker or crutches for exercise.

4. Join the YMCA/YWCA or a local health club and start swimming on a regular basis.
5. If money is not an object and you have spasticity, a Functional Electrical Stimulation bicycle has been shown to increase heart rate and endurance.
6. Obtain a VCR tape that shows you how to exercise and leads you through an exercise program at a wheelchair level. The McCluer Education and Resource Center has several examples of exercise tapes that can be checked out for review.

Your goal will be to achieve 50 to 80% of peak heart rate (as determined by a stress test or, in a normal young adult, use the formula: **220 minus your age**) for a duration of 20-30 minutes. You may need an abdominal binder and leg wraps to maintain a good blood pressure level. It is also important to protect your shoulder and upper extremity joints to prevent overuse syndrome and accelerating the development of arthritis. If your exercises cause you to have joint pain, review your exercise program with your therapist or physician.

So, do yourself a favor and get some exercise!



Incentives to Get You Working

It is easier than ever for individuals with disabilities to work. The Social Security Administration (SSA) is now offering improved *incentives to get you working*.

Cash Benefits While You Work

You can work a nine-month trial period without losing your regular monthly Social Security check and Medicare insurance benefits. This trial period does not have to occur in nine straight months. It can be a total of nine months over a 60-month period. When the trial period ends, your income is reviewed to see if you have reached "substantial" earnings. Substantial earnings for most individuals are when gross earnings for a full or part-time job average \$700 per month. For individuals who are blind, the substantial earnings amount is \$1170 per month.

Here is an example of this incentive. You take a job earning \$1000 per month. You work for three months but leave the job because you cannot do the work. However, your monthly benefits continue while you work and after you leave. A year later, you find a job that you can do. You work for another six months and earn \$1000 per month, still without losing any benefits. Now you have worked



a trial period of a total of nine months over a two year period while getting regular Social Security and Medicare benefits. If you continue to work, you will be evaluated by SSA to see if your gross earnings are considered substantial.

Help With Other Work Expenses

Your earnings may not be considered substantial even if you earn more than \$700 per month. You can deduct the cost of any item or service that you need to work. These deductible expenses can also be useful in daily living. You may be able to deduct the cost of a wheelchair, personal care attendant (PCA), prescription drugs, any specialized work equipment or transportation to and from work under certain conditions.

Here is an example. Your trial work period is over. Your gross monthly income is \$1000 per month. You pay \$400 per month for a PCA. The cost for your PCA can be subtracted from your gross earnings. Your adjusted, or counted, earnings are only \$600 per month, which is below the substantial earnings amount of \$700. This means you keep regular monthly benefits for at least 36 months, as long as your counted earnings are less than \$700 per month.

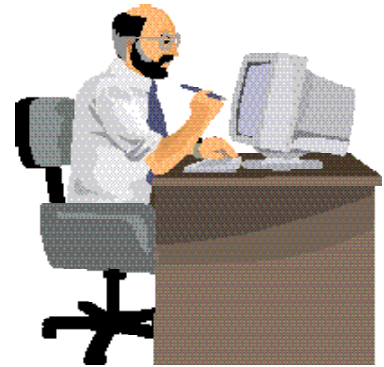
You will lose your Social Security check if your counted earnings are \$700 or more. But you can receive a check for any month that your counted earnings drop below \$700 per month if it occurs within 36 months after the nine-month trial period ends.

Medicare While You Work

You can keep your insurance no matter how much money you earn. Your Medicare insurance covers you during your nine-month trial period and continues for at least another 39 months. On October 1, 2000, this coverage expanded an additional 54 months for a total of 102 months. This is over eight years of insurance coverage after you start working. After that time, you can pay a monthly fee to keep your Medicare insurance coverage. This means that you can work and keep your insurance as long as you

have a disability.

Some individuals with very little income may qualify to have their state pay the Medicare fee, deductibles, coinsurance cases and other "out-of-pocket" expenses. Check with your local Social Security office to see if you qualify.



Leaving Your Job

You only need to call your local Social Security office to re-start your monthly Social Security check if you stop working within 36 months after your trial work period ends. There is no waiting period and no need to reapply. You have to re-apply for benefits following both the trial period and the 36 months after the trial period. If your new application is approved, you are entitled to another nine-month trial work period and incentives.

Another incentive started on January 1, 2001. For five years after both the trial work period and the 36 months, you will get six months of benefits while your claim is being processed. These payments will not have to be paid back if you no longer qualify for benefits.

These incentives can change. Call your local Social Security office with questions about benefits. The SSA is working to improve the way individuals with disabilities get answers to questions about ben-
Continued on page 8 - See "Incentives"

Life on the Internet

“You’ve Got Mail!” Ah, such sweet words. There’s nothing like e-mail in your computer’s mailbox to warm the cockles of your heart. But lately it’s getting harder and more time-consuming to deal with all the junk e-mail or so called “spam.”

Some e-mails are easy to dispose of—like those with a subject line about making money at home, easy weight loss or investment opportunities from people I don’t know. I really trash them fast (without opening them) if they have an attachment!

Other e-mails are harder to deal with. These contain suspicious or unsubstantiated content that often has been forwarded by a friend. Examples include warnings against

new computer viruses, offers to earn money just for forwarding e-mail, and personal accounts of alternative medicine use. Is there any truth to them or are they just big time wasters? Fortunately, there is online help available. Just check out the following web sites (you may need to precede these addresses with **http://**):

- Computer viruses, myths and hoaxes can be checked out at **www.Vmyths.com**.
- So called urban myths or legends can be uncloaked at **www.Snopes2.com**. This site is run by the San Fernando Valley Folklore Society and can give you the straight poop on thousands of rumors, schemes and stories.

- Alternative medicines, herbs and the misuse of prescription medication can be investigated at **www.Quackwatch.com**. This nonprofit corporation combats health-related frauds, myths, fads and fallacies.

Spinal Cord Disability Sites

The Internet is a great place to find information about a world of topics from the comfort of your home.

Have you visited these web sites?

- National Spinal Cord Injury Association at **www.spinalcord.org**
- Spina Bifida Association of America at **www.sbaa.org**
- National Multiple Sclerosis Society at **www.nmss.org**

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Better, Not Bitter

There is a saying: “The more things change, the more they remain the same.” In some ways, this could be applied to the outlook and activities of Jeff Watts. In January 1999, Jeff was working anywhere from 40 to 60 hours per week on the night shift as a Maintenance Technician. The main responsibility of a Maintenance Technician is to figure out how to make things work right when they go wrong. Jeff would leave work, arrive home early in the morning and help get his kids off to school and his wife off to work. On weekends he worked on farming activities.

While doing some farm work in July 1999, a 1000-pound round bale of hay slipped off a tractor spear and onto Jeff. He sustained a T-12 fracture. He went to Craig Rehabilitation in Colorado and continues now with rehabilitation therapy at Baptist Rehabilitation Institute and at a clinic in Benton.

Jeff sums up his perspective on life in very simple terms. “God has given me a talent of figuring out how to do things. God has me here to be better or bitter. Since this injury didn’t kill me, I know I have been chosen to do something better.” Jeff credits countless friends and well-wishers who lifted him up. “The walls in my room at Craig were literally covered with cards and letters from so many people. My wife has been by my side and my two children have been constantly involved.”

It has been just over a year since the injury and Jeff is very realistic about his future. “My long range goal is to return to work full-time. However, therapy is my most important task right now. I have plenty to live for. I have two wonderful kids, a wonderful wife, a supportive employer, more friends that I could imagine and a strong belief that God has a plan for me.”



Jeff Watts says, “Just don’t quit!”

Jeff is a living demonstration of his beliefs. He has been called upon to talk with other newly injured patients. He provides words from someone who has been there. “I let them know that what they are facing is nothing easy. I tell them, **‘Just don’t quit!’** Anyone can be a quitter. There is a purpose for all of us to be here.”

Internet

Continued from page 6

- National Amyotrophic Lateral Sclerosis Association at www.alsa.org

Reach Out and Touch Someone

People with disabilities are often less active in their local community than non-disabled persons. The Internet, however, is playing an increasingly important role in reducing the social isolation that persons with disabilities sometimes feel. This is especially true in Arkansas where Internet access (local call) is now available in most rural areas.

According to a survey conducted by the Harris Poll for the National Organization on Disability and sponsored by Aetna U.S. Health-



care, forty-eight percent of people with disabilities say the Internet has significantly improved the quality of their life compared with 27 percent of persons without disabilities. Computer users with disabilities reported spending nearly twice as many hours online and using e-mail as non-disabled users. (From *AXIS Newsletter*, Fall

2000). So, if you're not online yet maybe you should consider it.

Where Have You Been?

Where have you been on the Internet that you would like to share with our readers? Have you found any sites that have been particularly helpful to you as a person with a spinal cord disability? Or maybe just a fun site that you enjoy. How do you use your computer? Do you have any tips for others who might be considering a computer purchase? We would like to hear from you! E-mail us at arkscc@aol.com.

PS: Just for Fun

Want to be a millionaire? Really—no multi-level marketing scheme, no selling your soul, no grilling questions from Regis under hot television lights. For details visit www.Randi.org.



Disability Rights Center

Continued from page 1

What is PAIR?

Protection and Advocacy of Individual Rights (PAIR) has as its purpose to support a system in each State to protect the legal and human rights of individuals with disabilities who:

- (A) need services that are beyond the scope of services authorized to be provided by the Client Assistance Program; and
- (B) (i) are ineligible for protection and advocacy programs under Part C of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6041 et seq.) because the individuals do not have a developmental disability as defined in section 102 of such Act (42 U.S.C. 6002); and
(ii) are ineligible for services under the Protection and Advocacy for Mentally Ill Individ-

uals Act of 1986 (42 U.S.C. 10801 et seq.) because the individuals are not individuals with mental illness as defined in section 102 of such Act (42 U.S.C. 10802).

Federal Mandate - PAIR is authorized in the federal law Rehabilitation Act - (P.L. 105-220), 29 U.S.C. Sec. 794e. Funded by U.S. Dept. Of Ed., Rehabilitation Services Administration.

What is PAAT?

Protection and Advocacy for Assistive Technology (PAAT) is provided under the Assistive Technology Act. The purpose of the Act is to provide financial assistance to States to undertake activities that assist each State in maintaining and strengthening a permanent comprehensive statewide program of technology-related assistance, for individuals with disabilities of all ages; and, to identify Federal policies that facilitate payment for

assistive technology devices and assistive technology services; to identify those Federal policies that impede such payment; and to eliminate inappropriate barriers to such payment.

Federal Mandate - (PAAT) Assistive Technology Act - (P.L. 105-394), 29 U.S.C. Sec. 3001 et seq. Funded by the U.S. Dept of Education, National Institute of Disability and Rehabilitation Research.

The Disability Rights Center is located at 1100 N. University, Suite 201, Little Rock, AR 72207-6344. For more information, call **501-296-1775** (V/TTY), **800-482-1174** (V/TTY) or **501-2961779**(FAX). Their e-mail address is: panda@arkdisabilityrights.org. Check out the DRC website at www.arkdisabilityrights.org.

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New Videos and Books in the Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources please call the Resource Center at **501-296-1792** or **1-800-459-1517**. Some of the new additions include:

- **Pelswick: "I Won't Run, Please Don't Ask Me" (video)** is the first in a series of cartoons featured on Nickelodeon. Pelswick is a fearless 13-year old boy who just happens to be tetraplegic. Pelswick demands to be treated just like everyone else. The other characters in the story lines echo his contemporary attitude toward disability. Pelswick pokes fun at all of the different predicaments kids face on a daily basis.

- **A Circle of Friends (video)** is an informative video about the services and programs offered by the Baylor Institute for Rehabilitation. It features footage from the Annual Patient Reunion Christmas Party and individual patient interviews on how the Baylor Institute helped them become more independent.

- **The Comfort of Home (book)** is an illustrated step-by-step guide for caregivers. It features sections such as making the home safe, proper nutrition, how to avoid infections and illnesses and how to communicate with health care professionals to get the service you need. This book is easy to read and contains a lot of tools, such as checklists, to make a caregiver's job easier.

Incentives

Continued from page 5

efits. An Employment Support Representative will be available after January 1, 2001, to provide more consistent, accurate information about Social Security and Supplemental Security Income (SSI) benefits.

Note: Incentives to Get You Working was written by Phil Klebine, the editor of *Pushin' On*, with factual assistance from John A. Roberts, Rehabilitation Specialist, Social Security Disability Programs, Alabama Department of Rehabilitation Services.

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SPINAL COURIER
Arkansas Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207